

Background

Our knowledge about health service utilization at the end of life (EOL) among cancer patients is improving, but we have much more to learn.

Variations in service use by population characteristics have been identified:

- Elderly use less specialized palliative care
- Males are more likely to die in hospital

However, we do not know if these inequalities in utilization represent inequities.

Inequalities may be due to variations in patient *need or preferences for care*.

Inequalities due to patient need are inequitable, while inequalities due to preferences for care are not.

Currently, we have no information on patient need or their care preferences (wishes) at the EOL in population-based data.

Little knowledge of service use among people dying of diseases other than cancer.

Information gaps that we seek to fill

Information gaps to be addressed include:

- Estimation (or tentative definition) of “need”
- Data on decision-making and choices
- Inclusion of deaths due to other chronic disease

Approach

Obtaining information prospectively from dying persons is very difficult

- Challenge of identifying who is terminally ill
- Burdening the very ill
- Missing data due to poor function, cognition etc.

Alternatively, the experience of EOL care may be examined from the family’s perspective

- A “mortality follow back survey” approach

Mortality follow back surveys

A population-based design strategy to describe the events around death

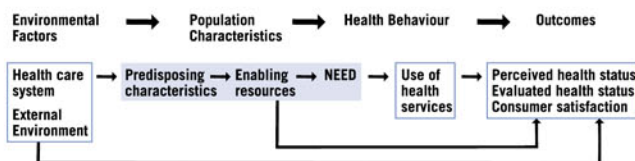
- Used in the UK, USA, Italy

Retrospective

Allows representative sampling of decedents

Limitation: validity of proxy responses

Linking EOL Care to Andersen’s Behavioural Model of Health Service Utilization



Project Goal

To examine the experience of EOL care among adults in Nova Scotia & to identify unmet needs, unfulfilled wishes regarding care preferences & satisfaction with EOL care using a population-based approach.

Specific Objectives

From the perspective of the decedent’s family or informal caregiver (informant), we will:

1. Estimate the prevalence of unmet need.
2. Estimate whether decedent care preferences (wishes) were fulfilled.
3. Estimate the satisfaction with EOL care received.
4. Examine the associations between age, sex & location of care with decedent unmet need, unfulfilled care preferences (wishes) & satisfaction with EOL care.

Method

Design

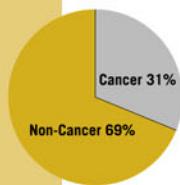
Population-based follow back survey

- Administered by telephone

Subjects

Death certificate informants of Nova Scotians who died during a 2 year study period (n=1200)

- Exclusions:
- <18 years at death
 - Death due to external causes, medical, surgical, pregnancy complications, self-harm
 - Incomplete informant contact information



Proportion of deaths in Canada due to chronic disease as the underlying cause, 2005

Sampling and Process

Population

All eligible deaths, (~15,000 over 2 years)

Sample

Total random sample of **3000** to obtain **1200** participants
Sampled in ‘waves’ of 500, every 4 months, among deaths occurring 4 to 8 months prior to sampling date

Initial Contact

By mail through Nova Scotia Vital Statistics

Researcher Contact & Survey Interview

Interested informants to supply their contact information to researchers



Survey Instrument

‘After-death bereaved family member interview’ (Teno J et al. 2004)

- Adapted for Canadian use
- Good validity, reliability
- 6 problem score domains; 2 scale scores

Questions pertain to last 30 and last 7 days of life

Analysis

Descriptive

- All items, problem score domains, scales
- Outcomes – proportion with unmet needs, unfulfilled wishes, satisfaction

Regression analysis

- Unadjusted & adjusted
- Linear & logistic
- Model interaction effects
- Modeling to assess confounding/modifying effects of additional covariates

So What? The Value of This Study

Provision of the first Canadian population-based estimates of patient need & care preferences at the EOL

Begins the examination of inequities in utilization & outcome for varying groups

For the first time, gather comprehensive information on all adult deaths due to chronic disease, not just cancer

Results will provide key new information to guide program & policy planning at all levels of government.

Measures

Unmet need

Physical comfort & emotional support (pain control, breathing problems, dealing with anxiety or sadness)
Focus on individual (personal care, treatment with respect & dignity)

Unfulfilled preferences (wishes)

Advanced care planning (medical treatment, procedures & provision of care consistent with decedent wishes)
Location of death

Satisfaction

Satisfaction scale score (patient focused, family centered care)

Other variables of interest

Predictors of interest

- Age
- Sex
- Location of care
- Hospital
- Long term care
- Home
- with PCP support
- with home care
- with no external support

Covariates

- Environmental factors
- Health system factors (residence, year of death)
- Population characteristics
- Predisposing characteristics
- Enabling resources
- Need (evaluated & perceived)
- Health behaviours

Assessment for Potential Bias

Selection bias

- Compare sample distribution of age, sex, cause of death to all eligible deaths (chi-square)

Informant recall bias

- Compare provincially funded health services provided to informant survey responses

Proxy informant bias

- Sensitivity analysis by adjusting for proxy respondent characteristics